




2019

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Jennifer Cademartori

UCSF Medical Center, jennifer101183@gmail.com

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Recommended Citation

Cademartori, Jennifer (2019) "One patient's experiences and expectations in the healthcare system: Complicated and critical illness with rare diagnosis described by his advocate," *Patient Experience Journal*: Vol. 6 : Iss. 1 , Article 2.

Available at: <https://pxjournal.org/journal/vol6/iss1/2>

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One patient's experiences and expectations in the healthcare system: Complicated and critical illness with rare diagnosis described by his advocate

Jennifer Cademartori, UCSF Medical Center, jennifer101183@gmail.com

Abstract

The health care business serves as a profession in the art of human illness. But unlike other businesses there is the human side, the patient experience. These patients are the “customers” receiving the care, but they, unlike customers at a retail store, are vulnerable and scared and must trust their lives in the hands of people they don’t know. The paradigm must change to reflect how the health care business is handled from the eyes of the person receiving the care from the first office visit, through the inpatient stay, to follow up visits. Patient focused training on all levels with the goal of seamless healthcare from phone to discharge to future visits to reach Value Based Health Care will help empower healthcare professionals and meet the expectations of patients [Lateef 2011]. As a health care provider for 25 years I have witnessed health care from a support staff perspective to a bedside RN to a Nurse Practitioner caring for complicated inpatients and outpatients. But the greatest learning curve for me was that as the wife of a complicated patient, my husband.

Keywords

Patient experience, caregiver experience, rare disease, narrative, emergency department, primary care

Introduction

Nine years ago, my husband was an avid surfer, runner, musician and entrepreneur in the construction business. When a difficult to diagnose illness struck him suddenly, our lives changed drastically. We went from a healthy active lifestyle to a life full of ED visits, hospital admissions, specialist visits, confusion and mistrust. A nurse practitioner by profession, my perception of the healthcare system changed drastically through this ordeal. Experiencing my husband’s care and acting as his advocate opened my eyes to the fractured nature of complex care, and how interactions with all levels of the healthcare system can impact a patients’ ability to trust providers. In this narrative, I will relay our experience from the onset of my husband’s symptoms, through his fraught journey to diagnosis and sequelae. It is my hope that this story underscores the need for coordinated and compassionate care that addresses the patient as a whole.

Narrative

My husband came home from surfing one day with a sharp pain in his left leg so severe that he had to crawl up the stairs. He wrote it off as a leg cramp, but when the pain continued well into the next day I sent him to his primary care doctor for an ultrasound to rule out a blood clot called deep vein thrombosis (DVT). His primary did not think it was a DVT, but reluctantly did the ultrasound anyway. Later he called me in surprise, “You’re right! It is

a DVT!” Working in the rare disease business myself, I asked for follow up with a hypercoagulable lab workup to rule out a clotting disorder prior to starting Lovenox and Coumadin. He agreed that he would order them. I was aware that this is not the standard workup for a first-time clot, but the circumstances seemed odd enough that I felt it was warranted.

This was just the beginning of what would become my husband’s serious medical issues, so my anxiety level was low. I had complete trust in his doctor’s judgement. His pain went away quickly after the initiation of blood thinning drugs, and he resumed his normal activities. At a six-month follow-up visit, an ultrasound revealed a partially resolved clot. His primary doctor prescribed a year of Coumadin therapy and decided to defer the hypercoagulation labs until after treatment, he had not ordered them yet. He felt confident that this was a provoked clot and not a sign of a systemic issue, though we could not think of anything that could have provoked it such as surgery, injury or period of prolonged sitting.

While on Coumadin, my husband stopped experiencing episodes of a burning sensation in his fingertips followed by “microthrombi” appearing under his fingernails, something that had occurred intermittently throughout the years. He came across an article in one of my NP journals describing a female patient with the same symptoms who had a blood clotting disorder called antiphospholipid syndrome (APLS). He exclaimed, “I have this!” I took one

look and dismissed his claim; this was typically found in young females. He insisted that I fax the article to his primary, and I did so to appease him but also with a sense of superiority as an experienced healthcare provider. I did not believe he had APLS. I will never forgive myself for that superior attitude.

At the one-year follow-up visit, a repeat ultrasound showed that the DVT was completely gone, and his doctor had decided not to run the hypercoagulation labs at all. A few months later, we awoke in the morning to find my husband's leg swollen to three times its normal size from foot to thigh; it looked like a water balloon. We immediately went to the ED, where an ultrasound showed an extensive clot. His doctor apologized for not running the hypercoagulation workup previously and finally sent off the labs. He was sent home once again on Lovenox and Coumadin. When the labs came back, he was diagnosed with antiphospholipid antibody syndrome.

Beyond Philosophy, a consulting firm dedicated to improving customer experience, described patient experience as dealing with the rational as well as emotional experience – to a patient their emotions and intuitive perception become reality in their mind.¹ At this point, the emotions we had surrounding my husband's illness had shifted. The easy trust and confidence we once had was gone. My husband was angry that his primary "hurt him," by disregarding his opinion and not listening. I had lost my own sense of confidence and superiority; my husband was more perceptive than his providers were and more perceptive than I was.

This time the Lovenox and Coumadin treatment did not go well. My husband was burning with fever every night. His INR, a lab that measures the therapeutic level of Coumadin in the blood, stayed below therapeutic levels even three weeks into still being on Lovenox (a heparin analog). His platelets were dropping and he was becoming anemic. During the third week, he experienced severe pain in his left lower chest with labored breathing. We both wondered if this could be a blood clot in the lungs (pulmonary embolism), while simultaneously wondering how that could be possible on blood thinners.

Once again, we were in the ED. A spiral CT revealed a pulmonary embolism (PE). He was taken to the ICU and started on a heparin drip. He was quickly diagnosed with a heparin allergy called heparin-induced thrombocytopenia (HIT). The Lovenox had caused the clot to break off from his leg and travel to his lung – his providers missed this even though he displayed the symptoms of HIT with twice-weekly lab monitoring. The heparin was discontinued and an IVC filter placed to prevent additional clots traveling to his lungs. He received a non-heparin IV anticoagulation therapy called Lepirudin. A more conclusive HIT assay came back definitively confirming

the diagnosis. His IVC filter was removed to allow for long acting anticoagulation therapy with Fondaparinux. No one could figure out his fevers, but his doctors assumed it was due to his injured lung. One doctor ran into me in the hospital hallway and blurted out, "he must have cancer!" She had forgotten that in this case I was the patient's wife and not a colleague. My husband was still in pain. I was exhausted and afraid to leave him alone because I no longer trusted his care team.

After one week in the hospital, he was discharged home. This began three of the most horrific months of our lives. We now had a diagnosis of APLS and HIT, but only after two DVTs and one PE. We were angry that his primary doctor had not ordered the labs which may have prevented the second episode altogether. Once home, he was up all night with a high fever and severe abdominal pain. The next morning we were back in the ED. His blood pressure was dangerously low, his liver enzymes and creatinine were elevated and he had hematuria. I looked at his labs and started to cry. He looked at his blood pressure and knew he was about to be back in the hospital.

Thus began the barrage of specialists. He was seen by nephrology, hepatology, gastroenterology, infectious disease, rheumatology and hematology/oncology. Lateef² explained in his value-based system that medical practice should be organized around conditions rather than specialties to increase value. In my husband's case, each specialty checked off their own boxes and ran their own tests. No one looked at my husband or his condition holistically. All of his tests (CT, Transthoracic Echo, EGD, colonoscopy, bone marrow biopsy) came back normal though he clearly was anything but. Over the course of three months in the hospital he became thin and frightened. His fevers and abdominal pain remained. When I was not there with him I feared that he had no advocate. It was hard for me as an NP not to trust my own profession.

The day of his planned discharge I found him curled up in his room with a 102 fever, complaining of abdominal pain. The resident was in the room and I asked him if he was really discharging my husband in this condition. Very curtly, he said that my husband was "just sensitive to procedures," and sent him home with morphine and Tylenol. He was also developing hives on his neck which had yet to be addressed. After a comprehensive review of patient expectations, Bowling et al.³ report that patients expect to be treated with respect and dignity, and to be given an opportunity to discuss concerns. These expectations were not met for us; we were rushed out the door and left feeling alone with unanswered questions.

It was not long after that my husband was back in the hospital urgently. An angiogram revealed microaneurysms in the medium-sized vessels to the kidneys, liver and

intestine suggesting a diagnosis of polyarteritis nodosum (PAN). This type of vasculitis carries a poor prognosis if left untreated.⁴ He was given a high dose of steroids and started on immunosuppression with Cytoxan. After three physically and emotionally draining months, we finally had a diagnosis. My husband was no longer isolated in the hospital getting weaker and more depressed with each admission, losing his will to live.

After the diagnosis and of PAN and immunosuppression treatment life began to resemble something livable. We were suspicious that the second DVT and heparin allergy had triggered the PAN and kept wondering if it could have all been prevented. It took about six months to get his PAN flare-ups under control during which he received a different immunosuppression medication, had a round of Rituximab and many steroid treatments. Six months after his Rituximab infusion, and while still on 20mg prednisone daily, his rheumatologist ordered him to stop taking Septra. In my own experience with such highly immunosuppressed patients, I kept them on Septra to prevent pneumocystic pneumonia (PCP). The rheumatologist assured us that it was protocol to discontinue, but surely enough only a few months later, I rushed him to the hospital once again where he was promptly diagnosed with PCP.

I became fearful at this point and hesitant to take him to the ED for fear of being admitted and further harmed by actual and perceived errors. As Lateef² stated, patients with unmet expectations have emotions ranging from disappointment to anger and may be less likely to seek further care due to a lack of trust in the provider. Lateef further states, "The days of absolute trust and blind obedience to doctors are over." We would wait out bouts of respiratory illness and I would treat him myself with antibiotics and the best possible at home supportive therapy. He would occasionally slip into SVT, and I would perform vasovagal maneuvers and give him an extra dose of beta blockers to convert to sinus rhythm. His health seemed to be improving though his quality of life continued to suffer; he was no longer surfing.

Four years after the diagnosis of APLS, HIT and PAN his cardiologist referred him for TAVR (transcatheter aortic valve replacement) to address his progressively worsening aortic valve stenosis. His specialist acted like a cowboy and told him that he can save or kill him during the procedure, but that he would certainly die without it. He was admitted to a state of the art hospital which felt like a first class hotel but lacked a human element. Torpie⁵ states that the patient experience is deeply personal however, all I saw when I looked around the halls were robots delivering supplies. After the TAVR my husband did not look right and was not moving. While I assumed he was still recovering from anesthesia, his ICU nurse laughed and

said "oh, he's just playing possum!" In reality he was having a small stroke.

Physically he was able to recover, but mentally he was depressed and losing his identity. When asked by a cardiologist how he was doing one day, he replied "I used to be someone." Hearing this I was speechless, with tears running down my face. During his complicated recovery filled with cardiac and stroke rehabilitation we both vowed to keep him out of the hospital. This unfortunately did not happen.

Since I originally wrote this in 2015, my husband was hospitalized many more times. We rescinded his POLST and he required life support beginning October 2017. He was diagnosed with interstitial lung disease in January 2017 and died of respiratory failure on January 5, 2018. I worked with the palliative care team and multiple specialists during his two and a half month hospitalization. They were still trying to save him, not seeing the whole picture of a dying man. Once I had a bedside nurse turn her back to me when I asked her for help, she put her hand up to my face, sarcastically said, "I'm just doing my job," and walked out of the room. This was 3 days before my husband died. There were many amazing nurses but it only takes one bad one to cause irreparable damage.

Reflection

During this entire experience, we were missing the guidance of a primary care provider or care coordinator. His original primary had left to teach full time without any sort of warm handoff to another provider. While a multidisciplinary team was treating him, there was no team leader to ensure that everyone was on the same page. There was no one to ensure that he was being treated as a whole person. The few times we did meet with a new primary physician he or she would look at my husband like a deer looks at headlights, and simply refer us back to the multiple specialties as if his case was too complicated to warrant a proper exam or even to ask how he was doing. Primary care is imperative for building a strong healthcare system and ensuring positive health outcomes. It should provide individual and family-focused care while promoting health.⁶ My husband's primary care experience could not have been further from this ideal and ultimately he was let down by those who should have been looking out for him.

It is my hope that care providers can learn from my husband's story and take the time to see through the eyes of their patients and patient's families. If a patient's concerns are dismissed, or if a provider rushes through a visit and does not appear to be familiar with the patient's history, all future encounters with that provider are affected and the patient's health can be affected as well. Adequate patient-focused training on all levels with the

goal of seamless care from the phone to admission and discharge and through the follow up and outpatient experience to achieve Value Based Care will help empower healthcare professionals to meet the expectations of patients². This goal can also be met with a coordinated team approach for the complicated patient, with the use of a primary care provider or patient liaison to tie in all specialties.

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